

Bogosian, A., Van Vliet, L., Craig, G. M., Fraser, L. & Turner-Cobb, J. (2016). Minding the gap and moving forward in children's long-term conditions: a vital role for health psychology. *British Journal of Health Psychology*, 21(3), pp. 493-498. doi: 10.1111/bjhp.12193



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Original citation: Bogosian, A., Van Vliet, L., Craig, G. M., Fraser, L. & Turner-Cobb, J. (2016). Minding the gap and moving forward in children's long-term conditions: a vital role for health psychology. *British Journal of Health Psychology*, 21(3), pp. 493-498. doi: 10.1111/bjhp.12193

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Minding the gap and moving forward in children's long-term conditions: a vital role for health psychology

Children with a long-term condition and their families are confronted with multiple biopsychosocial challenges. In this editorial, we outline the scope of the problem and then look at some examples of interventions for children with a long-term condition and how health psychology can inform and influence these. Health psychology theories are often not very well applied or reported and there is considerable scope for more health psychology input in this area (Prestwich et al., 2014). We discuss relevant issues and suggest directions for future research in which health psychologists might apply subject-specific theory and knowledge to further research and practice in the paediatric domain.

One in ten children will develop a long-term condition that limits their daily life substantially and demands extended care, supervision and self-management strategies (Yeo & Sawyer, 2005). These conditions include diabetes, neurodegenerative conditions such as, multiple sclerosis (MS), cancer, sickle cell disease, asthma, obesity and chronic pain. The first two conditions are drawn on in this editorial as examples of long term conditions but many of the issues raised apply equally to other conditions.

A recent study showed that the prevalence of at least one long-term condition over a 6-year period was greater than 50% during childhood (Van Cleave, Gortmaker, & Perrin, 2010). In addition to experiencing a poorer quality of life (Moreira et al.,

2013), evidence suggests that children and adolescents with long-term conditions have significantly higher rates of mental health problems compared to healthy children (Ferro & Boyle, 2015; Pinquart & Shen, 2011). Chronic physical health concerns in children and young people (6-20-year-olds) also have a significant impact on parental stress and family functioning (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010) and commonly imply a substantial economic load for families (Groenewald, Essner, Wright, Fesinmeyer, & Palermo, 2014). The majority of these conditions require daily self-management including medication administration and dietary and physical activity requirements. A recent WHO report (Davies, 2012) called for more research into patients' needs, and into potential health care service interventions to support children and young people (1-20 year-olds) with a long-term condition.

Children with a long-term condition have been frequently overlooked in the health psychology literature and little research has directly and systematically drawn from health psychology theories. For example, limited knowledge exists regarding behavioural methods for managing symptoms and disease progression in conditions with severe degenerative consequences for children such as MS. While there is no cure for this condition, physical activity has been shown to alleviate MS symptoms such as mobility limitations, fatigue, pain, and depression, which then improve children's quality of life (Charvet et al., 2014). In fact, children with MS, who reported greater amounts of moderate physical activity, had fewer fatigue symptoms and smaller lesions in the brain (Grover et al., 2015). However, children with MS report limited strenuous and total physical activity (Grover et al., 2015), a

behaviour profile that has also been positively correlated with lower self-efficacy and functional disability (Sawicki et al., 2015). However, to the best of our knowledge, there are no published interventions that help children with MS increase their physical activity, despite the potential positive effects this might have.

Interventions aimed at strengthening self-efficacy, such as those deriving from Social Cognitive Theory (Bandura, 1986), may lead to improved levels of physical activity in paediatric MS population. In children without a chronic illness, data suggests that the success of physical activity programmes can be enhanced if children feel that they have a sense of autonomy over their behaviour and if the activities are practical (Jago et al., 2015). A behavioural intervention that aims to increase physical activity through increasing self-efficacy and a sense of autonomy could be effective for children and adolescents with MS. Interventions will also need to take into account other barriers to physical activities identified by children with MS, such as perceptions of physical limitations (Sawicki et al., 2015).

Another condition with complex management issues for children and their families is diabetes. Health psychology theories specifically tailored for children and young people (0-18 years) could inform interventions in this area. Self-Determination Theory (Deci & Ryan, 2012) is among the most popular and influential theoretical model in guiding the design of interventions for self-management in adults with a long-term condition (Riley et al., 2011). In fact, in adults, a 16-hour nurse-led guided self-determination intervention had a statistically significant impact on Haemoglobin A1c levels from 3 to 12 months (Zoffmann & Lauritzen, 2006). However, this guided

self-determination intervention did not show statistically significant effects when used in adolescents compared to treatment as usual (Husted et al., 2014; Robling et al., 2012; Murphy et al., 2012; Katz et al., 2014). Hence, guided self-determination interventions may need further adaptations when delivered to children and adolescents.

Given the importance of autonomous motivation in the interventions for children, we need to explore how children internalise motivation when self-management guidelines come from parents and health professionals and might be linked to external reward or punishment. There is literature that suggests that providing tangible rewards undermines intrinsic motivation (e.g. see Deci et al., 1999), making the interventions less effective for children over time (e.g. Hardman et al., 2011). However, arguably, if care is taken to ensure the rewards are presented as a marker of achievement then this should increase feelings of competence and self-efficacy, which, in turn, may increase rather than decrease motivation (Lowe et al., 2004).

When developing interventions, it is important to consider that long term conditions can interfere with the process of developing independence and parents may become over protective. In adolescents with type 1 diabetes, parents may have unintentionally contributed to decreasing the adolescents' motivation for treating the disease and instead foster resistance, passivity, and a lack of motivation for developing self-management skills (Niemic et al., 2006; Leonard et al., 2005). Parents often describe having negative experiences involving struggle, frustration and worry about adolescent's diabetes self-management (Dashiff et al., 2011). They

report ways they have inhibited their adolescents' diabetes management by scolding, judging, and becoming emotional (Dashiff et al., 2011). Adolescence represents a key transition period to adulthood. It is possible that parental concerns and interference may lead to conflict between the adolescent's need for independence and compliance with self-management treatment. These competitive difficulties may have resulted in less engagement with self-management interventions in diabetes.

Moreover, we need to take developmental issues into consideration when translating self-management interventions to a paediatric population. Cognitive processes related to the pursuit of long-term goals are developed and refined in adolescences (Giedd, 2008). Further, health risk perceptions differ between adults and children, for example compared with adults, teenagers minimised the perceived risk of health-threatening activities (Cohn, Macfarlane, Yanez, Imai, 1995). We need to explore the risk perceptions in children and adapt interventions accordingly.

In addition to the appropriate operationalization of the theoretical frameworks and taking into account developmental issues another important consideration for future studies, is that of choosing the right outcome measures for interventions for children with a long-term condition. Different areas of a child's life can be affected by a long-term condition, such as school grades, self-esteem, hyperactivity and relationships with their peers. Outcome measures and treatment goals also need to take into account the full gamut of perspectives, considering views and emotions of the children themselves, their parents, and health professionals. This should also ensure

children's contributions are not squeezed out by parental concerns (Curtis-Tyler, Arai, Stephenson, & Roberts, 2015). Another consideration is the mode of communication used to elicit perspectives, especially in younger children. A good way for young people to communicate their experiences is through using computer-assisted interviews and phone apps. Apps have the potential to facilitate conversations with children about pain, discomfort and quality of life and help to track changes, even with very young children (Calam, Cox, Glasgow, Jimmieson, & Larsen, 2000).

To conclude, the current landscape presents ample opportunity for health psychology researchers to apply theory in interventions to improve health during childhood. However, the caveat applies, that the use of theory to design an intervention for children with a long-term condition does not always guarantee success (Ayling, Brierley, Johnson, Heller, & Eiser, 2015). Such interventions might need to be adapted to the developmental needs of this specific patient group and should pay attention to the choice of outcome measures. In paediatric obesity management for example the latest evidence suggests that narrowly focused behavioural interventions are unlikely to impact on change in the long term and the most effective interventions will require 'multicomponent and holistic' approaches that target the whole family and involve the support of teachers (PHE, 2015:30). The focus on children with a long-term condition and their families presents a significant opportunity for more in-depth exploration. There are self-management areas, such as paediatric MS, where there is no research on health psychology interventions, and there are areas, such as paediatric diabetes, where interventions need to be

developed and existing approaches based on adult interventions adapted further. Whilst interventions in adult populations are a challenge, intervening to improve health in childhood and adolescence present even greater multiple challenges. Yet the importance of intervening successfully in childhood has exponential benefits for subsequent health in adulthood (Turner-Cobb, 2014; Marmot, 2010).

A person-centred approach (Yardley et al., 2015) that focuses on understanding and accommodating the perspectives of the people who will use the intervention may be a useful approach when using specific theories and translating interventions from adult to child populations. According to the person-centred approach, developing an intervention is an iterative process that involves qualitative research with a wide range of people from the target user populations throughout the intervention development. These more inductive and participative approaches to intervention development may also address the issue of identifying meaningful outcome measures that can capture different aspects of the impact of a long-term condition from the perspective of children and young people. In turn, this will deepen our understanding of the impact of complex interventions and develop both insights and interventions that will be relevant to researchers, and clinicians that will improve health outcomes and quality of life for both children, young people and their families.

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